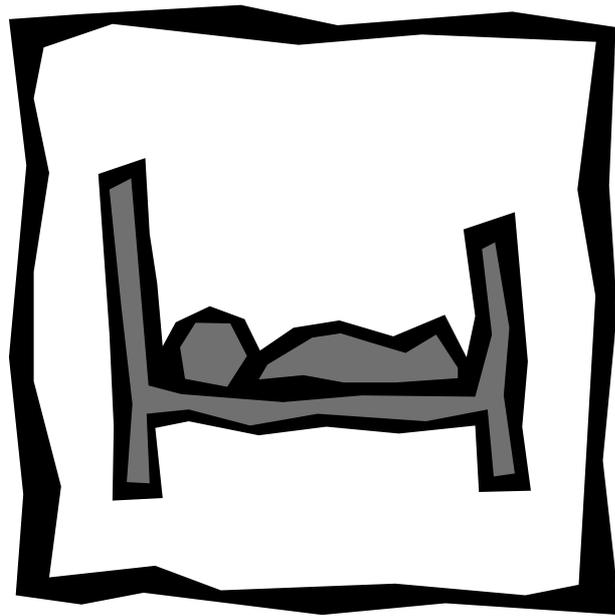


the  
forgotten  
children



a dossier of shame

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Tymes Trust is the longest running UK national support organisation for children and young people with ME, their families and the professionals involved in their care and education.

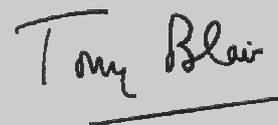
As such, we worked for three years on the government Chief Medical Officer's Independent Working Group, specialising in the children's section.

We were signatories to the published Report in January 2002, principally because of the recommendations made for children and young people.

## Prime Minister's Message

The Tymes Trust is a respected national voluntary charity offering a friendly, personalised service for children and young people with ME and their families.

It is committed to providing continuing and expanding high quality services, whilst maintaining a long established personal approach, specialising in providing practical solutions to problems.



Tony Blair

Tymes Trust is proud of its heritage. It began in 1989 when two young people with ME launched The Young ME Sufferer magazine. At that time, hardly anyone was aware that children suffered from ME.

# the war on fear

*this dossier has been compiled to raise awareness of the plight of children with ME*

**We constantly work with doctors, teachers and other professionals whose work is exemplary and whose attitude of compassion and dedication we applaud. Unfortunately, they still appear to be in the minority.**

Tymes Trust has evidence that the very systems set up by the government to help sick children and young people are being interpreted in ways that either ignore children with ME, or threaten, bully and intimidate them.

We take no pleasure in launching our War on Fear but it must be done. The Trust pledges itself to support children and young people with ME in their struggles for recognition, appropriate medical care and suitable education.

We are pleased to announce that the government is behind us and continues to support us.

the forgotten children - tymes trust

**Letter to Lord Clement-Jones CBE  
Patron of Tymes Trust  
Liberal Democrat Spokesman on Health in the House of Lords**

I share your concern that local authorities and schools should understand the particular needs of children and young people with ME.

I believe that the Tymes Trustcard is a very useful tool in helping to improve understanding of the needs of children and young people with ME and ensuring that they are able to continue to access education in a way that takes full account of their medical condition. I am therefore pleased to endorse the use of the Tymes Trustcard.

**Baroness Ashton of Upholland  
Parliamentary Under-Secretary of State for  
Early Years and School Standards**

The Tymes Trustcard is designed to be carried by pupils at school so that they can discreetly ask for help when they need it. It is endorsed by the Secondary Heads Association and signed by the school's headteacher.

# why a dossier of shame?

Tymes Trust fully recognises the government's commitment to providing appropriate health care and suitable education for sick children, including those with ME. We are impressed by the concern of ministers, MPs and Peers.

**However, the children and families whom we support report that many doctors, teachers and other professionals tasked with delivering this care and education are not only failing in their task, but are actively causing both distress and fear to children with ME and their families.**

This must stop.

Professionals not prepared to deliver services to these vulnerable children in accordance with the law must be held to account.

When my young daughter was very ill, had paralysis, couldn't sit up and struggled to eat from a spoon, our doctor shouted at her.

He told me that it wasn't as if she had MS. Another time he stormed through the house into her bedroom and flung the light on, then turned round and left. He said that social services were now investigating.

The rest of the staff behaved really nastily to my daughter and were obstructive. The paediatrician was willing to do a home visit but needed a GP's referral. The surgery staff told me they would send the referral to the hospital. We rang many times during the following weeks and each time were told that the letter had been sent.

Eight weeks later the paediatrician's secretary contacted us, concerned that she still had not received the letter. The GP's secretary admitted that it hadn't even been typed. We do not know if had been written at all. The paediatrician insisted it be faxed to her that day.

The school implied that it was my daughter's fault that she was ill. 'It's not as if she had leukaemia,' they said.

**Mattie Paul**

## **ME is the biggest cause of Long Term Sickness Absence from School.**

It is classified by the World Health Organisation under the heading 'Diseases of the Central Nervous System' (ICD10; G93.3). Viruses are known to be involved in its causation. Some children lose the ability to swallow and need tube-feeding for extended periods.

There is no definitive test for ME. But nor is there one for Multiple Sclerosis.

# risks of telling it like it is

The Trust's dilemma is that by publicly telling the truth about what is happening, we risk alienating the many doctors, teachers, social workers and others who are already doing a wonderful job.

However, without the truth, nothing will change. These dedicated professionals will continue to be obstructed and criticised by less enlightened colleagues.

**We do not want children and young people with ME and their families to think that every doctor they turn to for help will fail them.**

**Therefore before highlighting the negative statistics we have uncovered, we must emphasise the fact that we have regular contact with doctors who consult, support and endorse the work of Tymes Trust and are extremely supportive of their patients.**

Our Professionals Referral Service enables consultation by doctors with professional colleagues who are expert in ME and who are also members of the Tymes Trust Team.

We can also arrange for other professions to consult appropriately qualified and experienced members of the Team, for example, in various branches of the teaching profession and in social work.

On the medical section of the Team we have consultants and specialist GPs.

Our GP tutor runs PGEA-approved training events with our Executive Director, a former head teacher and medical educator. We believe in multi-disciplinary working and our training events are run in accordance with this principle.

The most recent event was run for Chelmsford Primary Care Trust who have requested more. We take every opportunity to dispel myths and misunderstandings about ME and those whom it strikes.

We encourage a caring and compassionate attitude to all people with ME and their individual needs, no matter of what age, as we believe that this is key to recovery.

I believe that Tymes Trust is fulfilling a greatly needed role. Many patients' bodies are in pain. I want patients to love themselves while they are ill. Many patients only love themselves as they used to be, when they were fit and active. When things are loved, they respond and begin to heal.

**Dr Darrel Ho-Yen**

**Consultant microbiologist, ME specialist and author**

**Medical Adviser to Tymes Trust**

# whose fault is it that kids relapse?

*in 2001 we took a close look at our advice line records*

90% of families contacting the Tymes Trust Advice Line reported the result of schools' demands on children with ME to include:

- more severe symptoms
- failure to recover
- relapse for months at a time

We were confirmed in our suspicion that unsuitable educational demands on children with ME are a key cause of relapse.

We spoke to consultant paediatricians and GPs who confirmed that this was a true reflection of their clinical experience.

## Case History

A GP asked our Executive Director to attend an educational meeting at his young patient's school. His patient had been so seriously ill with ME that she was thought to have a brain tumour.

She had needed to be tube-fed. She was very slowly recovering but was completely unable to cope with daily visits from a home tutor who insisted that she did physical activity.

Her brain had become so severely affected that she could not recognise the tutor from day to day.

Her mother was powerless to make the Local Education Authority take note of what was happening. Nobody would listen to her. She was desperate to stop her child from deteriorating in front of her eyes. She felt threatened and intimidated. At the meeting her request for another tutor, known to have a good understanding of ME and an excellent track record in the field, was aggressively refused on the grounds that it was not up to her to choose who was assigned to her case.

Only after a formal warning was given to the LEA about the possible severity of relapse as a result of their demands was some pressure temporarily removed. Eventually the family withdrew from state education as the only means of alleviating inappropriate pressure on their daughter. Her health improved as a result.

Statutory guidance from the Department for Education and Skills states that the education of sick children should be 'appropriate to their medical condition'. We have evidence that in ME cases this is not happening. The schools' legal duty of care is in our experience being widely disregarded.

# 2002/2003 : the statistics

*we invited families to tell us about their experiences in more detail  
we were shocked at the figures we uncovered*

- **76% were not satisfied with their education provision**
- 22% were satisfied but some said they provided it themselves
- 2% did not answer this question
  
- **87% had had to struggle for recognition of their needs**
- 13% had not had to struggle for recognition of their needs
  
- **81% had moved school to get recognition of their needs**
- 14 % had not moved school to get recognition of their needs
- 5% did not answer this question
  
- **63% had left state education**
- 31% had not left state education
- 6% did not answer this question
  
- **65% had paid for private tuition or distance learning**
- 33 % had not paid for private tuition or distance learning
- 2% did not answer this question
  
- **62% had felt threatened or bullied by attitudes from other children**
- 35% had not felt threatened or bullied by attitudes from other children
- 3% did not answer this question
  
- **84% had felt threatened or bullied by attitudes from professionals**
- 15% had not felt threatened or bullied by attitudes from professionals
- 1% did not answer this question

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These reports of bullying predominantly cited medical and educational professionals (as opposed, for example, to social workers). The majority of such reports cited both.

- **72% did not give a vote of confidence to State Education for children with ME**
- 14% did give a vote of confidence to State Education for children with ME
- 14% abstained from this question; some explained that they could not give an opinion as they were using private educational facilities

In total, 126 families shared their experiences with us. We know of many others who were either too intimidated to speak out or just too exhausted by caring for their children day to day to respond to our invitation.

# local education authorities

We also asked families to rate their Local Education Authorities according to how helpful they had been. There seems to be 'post-code prescribing' amongst Local Education Authorities.

**Only 40% of families found their Local Education Authorities helpful in meeting their needs, whereas 49% found them not helpful or very unhelpful.**

- 21% of families rated their Local Education Authority 'very unhelpful'
- 28% of families rated their Local Education Authority 'not helpful'
- 25% of families rated their Local Education Authority 'helpful'
- 5% of families rated their Local Education Authority 'very helpful'
- 10% of families rated their Local Education Authority 'as helpful as possible'
- 11% of families did not answer this question. Some said this was because they were not using LEA facilities

We note that it is not always the LEAs who believe themselves well informed about ME who actually provide the most supportive services. It is unfortunately difficult to persuade them to reconsider in the light of new information.

Many appear to believe, erroneously, that ME is a mental health disorder. If they say they do not believe this, they nevertheless often manage the illness in practice as if it were.

Some appear to allocate ME a 'standard' procedure involving:

- the refusal or discouragement of home tuition
- pressure on the family to undergo counselling
- long delays in provision
- early and repeated return to school even if this has already been proved to cause relapse

**The help that children get appears to be dependent on the individual school and even the individual teacher rather than on their entitlement to help and support. Overall, 56% of families had experience of schools being either 'not helpful' or 'very unhelpful'.**

The Tymes Trustcard is wonderful. It has made a great difference to my daughter Cheryll with school.

**Julie Neyt**

# main complaints from families

- Children face inappropriate pressure from schools to get back to classes
- Teachers are resentful, threatening and unkind, making cruel remarks to children with ME when they manage to attend a lesson
- Teachers are untrained in ME so parents have to give them information from support organisations
- Because the information comes from support organisations, teachers often ignore the advice contained in it
- Children are pressurised to follow the entire National Curriculum despite their neurological disabilities which make it impossible to achieve anything worthwhile in more than a few subjects at a time
- Schools are reluctant to make special arrangements for examinations, do not inform parents about this and often deny that such arrangements are possible
- Schools are often hostile to the child or parents, expressing disbelief when they explain that even though the child can make an effort for a while, the after-effects are often very severe
- Teachers question the medical diagnosis and are not prepared to follow the advice of GPs
- Children ask parents not to complain for fear of bullying by teachers

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Families tell me that the biggest problem they face is when the child with ME is pushed to try and get back to normal too quickly. They almost always relapse.

**Dr Alan Franklin**  
**Consultant Paediatrician (retired)**  
**Member, Chief Medical Officer's Working Group on CFS/ME**  
**Medical Adviser to Tymes Trust**

Lockerbie Academy and home tutor Mrs Horn were both awarded a Tymes Trust Angel of 2000 Award for their continuing understanding and support to 14 year old Matthew Howitt.

All the staff worked tirelessly to help my son Matthew continue with his tuition, with constant support from his home tutor. Mrs Horn took Matthew to school just to visit the library when he was well enough. She reads everything I give her on ME, usually from the Tymes Trust.

**Margaret Howitt**

# response to government reports

In early 2002, two new government reports were published that directly concern children and young people with ME.

The report of the Chief Medical Officer's Independent Working Group on CFS/ME was published in January. Tymes Trust played a major role in the Children's Section of the Working Group.

Soon afterwards, the Department for Education and Skills published statutory guidance entitled 'Access to Education for Children and Young People with Medical Needs'.

Many professionals seem unaware that the Department for Education and Skills also endorses the educational recommendations in the Chief Medical Officer's Working Group Report.

We are sad to report that in our experience, in many areas of the country, neither of these documents is being interpreted in the spirit in which they were written.

Main difficulties reported to us are:

- **The attitude of schools and support services to children with ME has become increasingly hostile**
- Home and Hospital Tuition Services increasingly enforce attendance at special units and refuse to offer or continue home tuition, apparently unaware that 'Access to Education' makes it clear that home tuition must be provided where needed
- Support services are re-naming themselves 're-integration services' and some state that this is their main aim, despite the fact that their main aim is supposed to be 'enabling children and young people to access education appropriate to their medical condition'
- Typical comments reported by parents who request home tuition include:
  - 'The tail doesn't wag the dog'
  - 'We won't be blackmailed'
  - 'Your child is simply school phobic'
- One young teenage boy said he felt 'violated' by the teacher who had telephoned him at home in his mother's absence. His mother found him in the bath, trying to scrub himself free from this feeling

# intimidation by medical professionals

Out of the 84% of our families who felt bullied or threatened by professionals, 88% specified doctors as being even more responsible than teachers.

Knowing already that inappropriate educational demands were a key cause of relapse, Tymes Trust had decided to investigate what had gone wrong with the education system from the families' point of view. This is why we asked such detailed questions about schools and Local Education Authorities.

We have been hearing for some time through our regular work that unsympathetic doctors are responsible for inappropriate treatment of their young ME patients and that many patients report being made worse through inappropriate physiotherapy or graded exercise programmes.

In particular, we know that Child Protection issues have arisen in a number of cases out of the misconception that parents are neglecting or intentionally damaging their children.

When the BBC Panorama programme investigated this phenomenon in 1999 Jane Colby, who had by then worked with all the major ME charities and who is now our Executive Director, carried out a survey with the BBC. The statistics revealed that:

- 59% of families were told by doctors that their children's illness was caused by psychological problems – this seems to indicate a clear misunderstanding by doctors of the nature of ME
- 15% of families were told that it was their own psychological problems that were causing the child's illness
- 5% had undergone psychological treatment and their parents all reported it either had no effect or made their children worse

Two of the most disturbing statistics were:

- 4% of parents had been branded with the condition Munchausen's Syndrome by Proxy, in which a person harms another in order to gain attention. This syndrome was always a controversial diagnosis and has since been renamed; many doctors dispute that it exists at all as a separate entity from child abuse

National statistics at that time showed that Munchausen's Syndrome by Proxy affected just one in 100,000 families.

- 7% of children from families questioned had been subject to child protection proceedings; court proceedings had either been threatened or carried out

**If representative, this implies that 7 out of every 100 children with ME will be threatened with being taken away from their parents.**

It is now three years since that survey was done and in that time, the Trust has seen many more cases. So far, none that we know of have turned out to be proven cases of child neglect or child abuse.

Here we see how difficult it is to separate the medical from the educational systems. For it is typically the fact of a child's non-attendance at school, coupled with medical misunderstandings about the condition, that together trigger the Child Protection procedures.

Having a child with ME is like having first hand experience of a medieval court. Every day we face the prospect of some ill-informed authority dictating damaging treatment to our child.

#### **Father of child with ME**

**There is now an urgent need for both doctors and teachers to be well trained in the needs of children with ME to avoid such widespread misperception of why the child is absent from school.**

Doctors also need to know of the modern ways to deliver education.

The Trust has produced a guide to the education of children with ME for GPs, who are at the coal face and can recommend modifications to the child's education far more quickly than the consultant.

Everything needs to be tailored specifically to the individual young person.

**Dr Nigel Hunt**

**GP; GP Tutor**

**Member, Chief Medical Officer's Working Group on CFS/ME**

**Medical Adviser to Tymes Trust**

Of an estimated 300,000 people with ME in the UK, 25,000 are thought to be children. A bout of ME typically lasts over 4 years with relapse being possible even after apparent recovery.

During this time most children are not well enough to attend school full-time. Even after what they described as 'recovery', in a study in the year 2000 by Rangel et al, 47% were found still to suffer symptoms and one third were not able to attend full-time.

Unfortunately, calling the illness 'Chronic Fatigue Syndrome' has led many to think that the child is merely tired when in fact there are profoundly disabling effects upon the brain and central nervous system. These children are delicate and relapse can easily be provoked.

**Jane Colby**

**Former Headteacher**

**Executive Director, Tymes Trust**

**Member, Chief Medical Officer's Working Group on CFS/ME**

# what can GPs do to help?

*the tymes trust focus group was recently formed from our members and their families for consultative purposes*

The Group was asked:

**What sort of support would you like to see given by GPs to young people with ME and their families?**

An important recommendation which came out of this exercise was that:

**GPs need to be supportive from the very beginning of a possible diagnosis for ME. This is because deterioration can set in quickly when help is delayed.**

The same finding emerged from group discussions at a recent Inter-active Forum for GPs, teachers, social workers and other professionals together with people with ME and their carers.

The meeting took place at Springfield Hospital, Chelmsford on 30 April 2003 and was run by Tymes Trust Medical Adviser Dr Nigel Hunt and Executive Director Jane Colby.

The friendly and open atmosphere was very encouraging and demonstrates that it is perfectly possible to cut through dogma, prejudice and misunderstanding when people sit together in friendship with the clear intention of seeing one another's point of view.

Everyone agreed that sadly, many doctors, teachers and others 'listen but do not hear what is being said'.

Parents of children with ME and adult patients said how valuable it was to experience the doctors' side of the patient/doctor equation. We firmly believe that this is the way forward and that similar meetings would be of benefit in other areas.

Other Focus Group recommendations for GPs were:

- Do not force children back to school
- Support home tuition and appropriate education generally
- Liaise with schools, colleges and universities
- Provide counselling services where needed, involving the whole family
- Give details of ME support organisations and consult their literature
- Provide home visits for bedbound or housebound patients
- Give details of agencies that can supply support such as patient-sitting, bed-bathing and occupational therapy

- Provide information about benefits and support applications
- Keep an open mind about the condition
- Provide information leaflets in surgeries
- Empower patients and their families to choose which treatments, if any, to follow
- Support decisions to self-manage the illness without following programmes of CBT or graded exercise since most cases improve over time without treatment
- Maintain confidentiality and do not pass personal information to other agencies unless strictly relevant
- Understand the potential severity and long term nature of the illness
- Understand that this illness is neurological and is not just being tired
- Arrange follow-up appointments (3 or 4 times per year) to see how the child is coping

The valuable point was made that without regular follow-up, the child is only seen when there are new or worsening symptoms. Parents need to be reassured that they are doing the right thing and children need not to feel forgotten.

It was also suggested that contact between the GP's ME patients might be organised for mutual support, since they will probably live reasonably close to one another.

My first GP didn't diagnose my illness. His attitude was to go to school and exercise, which was harmful. I have now changed GPs.

**Anna Daffin (16)**

Recurring themes were:

- the need for doctors to believe what their young patients tell them
- the importance of listening carefully to what is said
- a supportive attitude

It is imperative that both parents and the medical profession are listened to when making provision for school or education.

**Mrs Tez Cabrera and Teska, her 13-year-old daughter**

Our GP totally disregards anything we say with a statement of 'Our surgery doesn't believe in ME. It took months and numerous letters to get a domiciliary visit by our paediatrician, which the paediatrician had actually wanted to do, but couldn't unless asked by the GP.

**Salli Noble and Tiffany, her 15-year old daughter**

# what do others say?

*others have studied the experiences of young people with ME  
all we have come across confirm our own findings*

The following passages are taken from *Does Your Child Have a Hidden Disability?* by Jill Curtis.

*Helena told me that once she and her daughter had accepted the diagnosis of ME, they began to relax, but then the problems started. [...] Helena said her worst battles were with the education authorities who, once they could see some improvement, wanted to pile on the pressure for her child to 'catch up'.*

*Again and again I heard from parents who had been told that their children's illness was due to 'psychological problems'. In 2001 The Times Educational Supplement Scotland published an article where ME was described as 'Mother's Encouragement' to stay off school. ME, more than any other invisible disability, seemed to carry this stigma. Needless to say, the paper subsequently had to print a good deal of information to the contrary, and an editorial distancing themselves from that statement.*

In *Shattered*, Lynn Michell writes about young people and professionals.

*My own GP was very fond of the word 'psychosomatic'. She would say, 'You do have a tendency to somatise your symptoms.' Because my son weighed eight stone when he was over six foot tall, she used the label 'anorexic', despite our telling her, repeatedly, that even with nausea he ate and ate and ate.*

*Both Ruby and Kirsty talk about how much they loved school, but such protestations fell on deaf ears. [...] Josh describes how when he could not concentrate in the classroom, he was told by teachers that he was stupid and was not making any effort. Staff accused him of inventing illness to avoid his work.*

In Sydney, Australia, the Alison Hunter Memorial Foundation ran the Third International Clinical and Scientific Conference on Myalgic Encephalopathy / Chronic Fatigue Syndrome in December, 2001.

The presenter of the first section was Durham consultant paediatrician Dr Nigel Speight. Basing his observations upon years of experience he said that some doctors simply 'can't stand the patient being so ill'.

In such circumstances, and unable to effect a cure, it is all too often the case that the doctor's feeling of guilt is displaced onto the patient, who is blamed for having an incorrect 'illness belief' and thus for not recovering.

Tymes Trust finds that the evidence from its members actually suggests the reverse; that many doctors have an incorrect 'treatment belief'.

Therapists who practice Cognitive Behaviour Therapy, when challenged, point out that it is not a cure. The safest way to look after patients with ME seems to be to encourage them to pace life carefully and live within their present limits.

Experience shows that living within the patient's energy envelope is an effective method of self-management leading over time to improved strength. It is generally counter-productive to try and force the pace of recovery.

The secret of living with ME is to live within its barriers. If you live within the barriers, then the barriers expand.

**Dr Darrel Ho-Yen**  
Consultant microbiologist, ME specialist and author  
Medical Adviser to Tymes Trust

Between 1991 and 1995, consultant microbiologist and ME expert Dr Elizabeth Dowsett and former headteacher Jane Colby carried out the largest ever study of ME. Their paper was published in the *Journal of Chronic Fatigue Syndrome* in 1997. From the Abstract:

*A study was made to determine whether the recognition of multiple cases of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) in one school is an unique experience. A five year retrospective period prevalence survey (1991-1995) was collated from sequential reports made in six English Local Education Authority (LEA) areas.*

A school roll of 27,327 staff and 333,024 pupils was investigated. ME was found to cause 51% of all long-term sickness absence in children, far greater than any other condition. Other, smaller studies since that time have repeated this finding.

ME was found to occur in clusters, in line with the epidemiology of diseases triggered by infection. The authors recommended that 'redirection of research to special educational needs and to early diagnosis of infectious agents which can trigger ME/CFS in schools might prevent, at low cost, much chronic illness and education deficit'.

All living organisms have a capacity to heal and I think there is no reason why a child with ME, given the right support, will not self-heal.

**Dr Alope Agrawal**  
Consultant Paediatrician  
Medical Adviser to Tymes Trust

# appendix 1

## *key quotes from the report of the chief medical officer's working group on cfs/me (department of health 2002)*

All statements are contained in the text of the Report; they are not our interpretation of the Report, but direct quotes from it. Taken together they comprise key information on the illness, on how it affects children, and on how it should be managed, including educational management (endorsed by the Department for Education and Skills).

### **Nature of the Illness and Symptoms**

- Chronic Fatigue Syndrome (CFS/ME) is a genuine illness and imposes a substantial burden on the health of the UK population. CFS/ME affects many people and their families in the UK and elsewhere in the world.
- Many of the symptoms of CFS/ME suggest dysfunction of the central nervous system.
- Characteristic or common symptoms include: persistent/excessive tiredness or fatigue; cognitive impairment; postexertional malaise; pain; sleep disturbance; recurrent sore throat; digestive disturbances; intolerances eg of certain foods, medications and alcohol; other symptoms apparently related to the neurological and/or endocrine systems.
- Activity beyond the level that an individual can usually tolerate will prompt a delayed worsening of symptoms.
- Early recognition with an authoritative, positive diagnosis is key to improving outcomes.

### **Children and CFS/ME**

- Children and young people (defined as being of school age) do get and are profoundly affected by CFS/ME, contrary to some professional and public perceptions.
- In children, the commonest age of onset is 13-15, but cases can occur as young as 5.
- A diagnosis in the young must be especially prompt, accurate and authoritative, and second opinions are needed if doubt exists.

### **Time-Scale for Diagnosis in Children**

- When a child or young person has symptoms affecting school attendance for at least four weeks, active steps should be undertaken to identify the cause from a list that includes CFS/ME.

## Spectrum of Severity

- Some children and young people with CFS/ME are so severely affected by the disease that they become bed-bound, with a similar degree of cognitive and physical impairment to that experienced by patients with severe neurological conditions.

## What clinicians can do

- Listen to the patient, recognise and believe his or her individual experience.
- Acknowledge uncertainty and the impact that this has on the patient, family and carers.
- Provide information on and discuss: the nature of the condition, approaches to self-management, helpful therapies, and how to access other agencies for support and services.
- Agree a name for the condition. [The Report suggests CFS/ME.]
- Give advice on symptomatic treatment.

*The Report recommends that patient organisations be contacted for support.*

## Treatment/Management

- No management approach to CFS/ME has been found universally beneficial, and none can be considered a "cure". Patient responses suggest that [...] all can cause harm if applied incorrectly.
- As with many chronic conditions, the emphasis should be on improvement and adjustment rather than "cure". The goal of rehabilitation or re-enablement will often be adjustment to the illness.
- Experience suggests that provision of a wheelchair or other mobility aid does not stop patients working towards mobility without the equipment in the long term; indeed, such aids probably assist remobilisation, with suitable supervision.
- The notion of "once in a wheelchair, never out" is prejudicial: each case must be assessed according to clinical and functional need.
- Although there is no cure for CFS/ME, the condition has been found to improve in most patients both with and without\* treatment; it is good practice to encourage patients to become experts in self-management and to choose between treatment options. [\*Patients may therefore decline active treatment.]
- Most children who are missing school can be cared for and managed in their homes, with follow-up in primary care or by a specialist such as a community paediatrician.
- Careful listening and respect for parents/carers' opinions are important factors.

## Educational Management

- Nearly all children who are severely affected and many who are moderately affected will require the provision of home tuition and/or distance learning. Some young people will be too severely affected by their illness to participate in any form of education, even at home.
- An educational plan is not an optional extra but an integral part of therapy.
- A young person who is likely to have special needs, including home tuition, should be identified early in the diagnostic process, preferably by a GP or paediatrician.
- Specifically, a young person with CFS/ME should never be forced to study but instead should be encouraged to set a pace that is likely to be sustainable, then have their progress regularly reviewed.
- Some more severely disabled children may need home tuition and/or distance learning on a longer-term basis. In addition to the time of a tutor or therapist, this may require information and communications technology, which can also help improve social contact.

## Child Protection

- In cases of CFS/ME, evidence clearly suggestive of harm should be obtained before convening child protection conferences or initiating care proceedings in a family court.
- Neither the fact of a child or young person having unexplained symptoms nor the exercising of selective choice about treatment or education constitutes evidence of abuse.

## Prognosis

- Overall, there is wide variation in the duration of the illness, with some people recovering in less than two years, while others remain ill after several decades.
- A minority of those with CFS/ME remain permanently severely disabled and dependent on others.
- Most people with CFS/ME can expect some degree of improvement with time and treatment, so a positive attitude towards recovery needs always to be encouraged.

# appendix 2

## *tymes trust services and further reading*

The Tymes Trust Advice Line is open from 11:00 am to 1:00 pm and from 5:00 pm to 7:00 pm Monday through Friday; telephone 01245 401080.

The Trust's Professionals Referral Service enables doctors, teachers and other professionals to consult ME experts in their own fields.

The quarterly *Tymes Magazine* for families and professionals is free to those under 26 years of age. Subscriptions are £9.75 per annum otherwise.

Further information is available online via Tymes Trust's partner website [www.youngactiononline.com](http://www.youngactiononline.com).

**Long Term Sickness Absence due to ME/CFS in UK schools;  
an epidemiological study with medical and educational implications**

Dowsett EG, Colby J  
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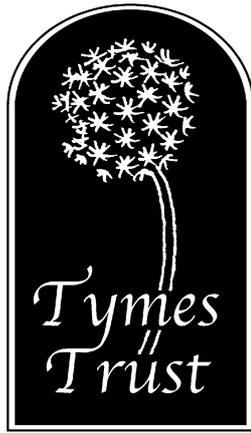
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